

# **Do you need compassion to work in palliative medicine?**

"Moments of exquisite compassion...made the unbearable bearable" (Schwartz, 1995)

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## ABSTRACT

Compassion is deemed a “basic social emotion” (Nussbaum) and decreed an NHS core value – yet, what does ‘compassion’ really mean? Moreover, why is it so important, how can we deliver it best, and how do we measure achievement here?

This essay will argue that compassion stands apart from other forms of interpersonal engagement as a deeply human recognition of another’s suffering which inherently motivates action to do something about this. There are two inextricable elements here: the role of suffering, and the resultant call to action it motivates.

The role of compassion pivots on suffering, and thus, our interpretation of suffering and what we consider its upstream cause: the problem to be fixed. Palliative medicine here stands apart, priding itself on the holistic care of what is important to the patient; thus, the symptoms problematic to the patient are the problem, rather than the underlying cause per se.

Compassion drives motivation to act; medicine equips us with the tools by which we can respond to this. Thus, compassion has been described as a ‘calling’ to healthcare for many who join the profession, and perhaps it is when these tools seem to fail that compassion fatigue takes hold. Though this is beyond the scope of this essay, compassion fatigue is considered a form of burnout directly related to the experiences of a caregiver.

Thus, compassion is central, and its outcomes stem firstly from our perspective of the issue at hand and secondly from our ability to drive change. The ability to recognise suffering in another and be motivated to help has relevance far beyond work in palliative medicine; perhaps this form of interpersonal engagement extends to humanity itself.

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To answer this question, let us turn it on its head: could you work in palliative medicine *without* compassion? There are no real barriers to doing so; however, would you *want* to do so? This essay will argue that compassion is a motivator, spurring action to alleviate suffering. This acts at the doctor-patient level but also upstream of this, at the level of medicine itself and higher still at the level of what it means to be human.

### WHAT IS COMPASSION?

Etymologically, compassion originates from twelfth century Latin, *com* (with/together) *pati* (to endure, to suffer). This gave rise to fourteenth century Old French *compassioun* (a feeling of pity or sympathy, excited by another's suffering). The Latin *pati* (“to endure”) is the past participle stem of *passionem*, which itself gave rise to the late twelfth century *passion*. By the 13<sup>th</sup> century *passion* was used to describe the suffering of martyrs, and by the 14<sup>th</sup> century to mean a “strong emotion or desire” (as for the Greek *pathos*). Linguistically, therefore, compassion is rooted firstly in suffering (particularly underserved suffering); and secondly in the deeply ‘passionate’ response this evokes in the observer.

The basic meaning of compassion stands as it does linguistically: to suffer with and for another. Conceptually, however, compassion is more nebulous: in fact, for Charlton[1], it is “almost indefinable”. It may be considered a form of engagement, related to sympathy, empathy, and to a lesser degree pity; the latter has gained connotations of condescension and superiority unwelcome in medicine and will not be discussed at length here.

Jeffrey[2] delineated important distinctions between sympathy, empathy and compassion. Sympathy is a reactive concern, in line with Hume's[3] conception of sympathy as sharing the feelings of another, “depend[ing] on the relation...to ourselves”. Sympathy may provoke action to alleviate distress, but this is fundamentally to make the observer feel better rather than to change the sufferer's experience. Empathy is similarly affective, but has further behavioural, moral and cognitive dimensions; this cognitive element introduces a rationality to empathy which can be a distancing agent that “gets in the way”[4]. Contrastingly, compassion “does not necessarily involve cognitive understanding”; it is deeply reactive and uniquely motivating, spurring the observer to intervene. Thus, Youngson[5] defines compassion as “a motive: the humane quality of understanding suffering *and wanting to do something about it*”, echoing Nussbaum's[6] view of compassion as a “basic social emotion”.

### COMPASSION IN ACTION

Sinclair et al[7] brought Jeffrey's delineations of sympathy, empathy and compassion into sharper clinical focus by asking palliative cancer patients for their perspectives; across the 53 subjects, compassion was distinguished and preferred, for its “action oriented” approach. They framed a stepwise hierarchy of engagement: sympathy (a pity-based response) facilitates information-

gathering, enabling active imaginative empathy (an affective response) and subsequently deeper compassion (a virtuous response), provoking action to alleviate suffering. Their data identified key features of compassion as being action oriented; motivated by unconditional love from an altruistic responder; and accompanied by “small acts of kindness” going “above and beyond”.

Compassion therefore inherently motivates action; medicine equips us with the *ability* to act. Thus, Youngson[5] considers that “compassion [was] what called most health professionals to join their profession”, and the distinction of compassion as an NHS core value – as it stands in many other health systems – gains nuances upstream of the point of delivery of compassionate care.

Action for Mannix[8] is the “coping mechanism” of healthcare professionals who “deal with suffering every day”; when our actions are “declined, we feel disempowered and our helplessness opens the gates to sadness”. Perhaps this sadness is compassion without interventional action, paralleling the oft-cited social construct of grief as ‘love with no place to go’; in turn, perhaps this sadness seeds compassion fatigue.

Action then is significant, as is the desire to act; thus, this desire could conceivably pose a risk to clinical judgement. We recognise ourselves that the ammunition of modern medicine is not always appropriate: studies show that healthcare professionals often want for themselves far less intervention than they offer their patients. It is key then to ask these vital albeit difficult questions to enable patients themselves to draw the lines.

Perhaps social perspectives of medicine are relevant here. In the media, disease is often portrayed a ‘battle’ and palliation a ‘giving-up’; but how often is this view upheld in reality? The Royal College of Physicians[9] recently reported doctors’ concern that patients perceive death as a failure to be a deterrent to initiating end-of-life discussions. However, patients spoke to the contrary and found end-of-life discussions to be both desired and empowering.

Perhaps another issue is the object of compassion: patients, but also their families. Giving the patient the opportunity for self-determination is in itself an act of compassion, yet initiating these difficult conversations may feel far from compassionate at the time. Compassion demands courage and foresight here, aiming to avoid situations in the future that could be even more challenging, particularly for the patient’s family. The conversation is more important than its outcome, opening the door to thoughts that may enable potentially transformative advanced care planning.

Way and Tracy[10] set out three key elements to compassion: 1) recognising another’s suffering, 2) relating to the other, and 3) responding to alleviate their suffering. They highlighted “the integral role of communication” here, particularly in the context of relating to the other. The significance of communication extends further, into recognising the ceilings of compassionate care. Wong[11] depicted this in her discussion of her son’s rapid deterioration to end of life, and how she felt communication broke down as staff tried to maintain “hope as a humane response to uncertainty”. As time passed and her son’s prognosis changed, lack of “ongoing communication of his status” cost the family “time to think and to discuss”. She felt that staff failed to communicate effectively the “questionable” nature of her son’s “quality of life upon...unlikely survival”; the assumptions that had to be made in the absence of open discussion led to the feeling in hindsight that “the fight to save his life went on too long”. Communication, so key to compassion, “was not integrated” and perhaps emotional resonance became dominant here; “the staff could not resist our endless, unspoken plea to save our son”.

Communication facilitates understanding. For Jeffrey[2] perspective is also critical; whereas empathy is ‘walking in another’s shoes’, taking your experiences into their situation, compassion is “understand[ing]...that person’s situation...in the context of their life”[12]; to consider how it would be to be *that patient* in that position, rather than *to be in* their situation.

This perspective is also protective; at times, everything can feel a little too close for comfort. Wolterstoff’s[13] invitation, “Come sit beside me on my mourning bench”, eloquently illustrates Dame Cecily Saunders’s[14] point that we must “learn how to feel [with] patients without feeling [like] them if we are to give the...support they need”. Adopting an *other*-oriented, not *self*-oriented perspective – for Halpern[15], a “decentring” – enables us to accompany the distressed without becoming so ourselves.

### INTENTIONALITY OF ACTION

Compassion is predicated on action; the observer is spurred to intervene. Motivation is the coupling element here, something which is particularly interesting to consider in the context of some of the challenging decisions confronted in palliative care. One such example is the use of analgesia and sedation at the end of life; these medications are intended to alleviate unwanted distressing symptoms including pain, breathlessness and agitation. The doctrine of double effect has been often invoked here, whereby detrimental side effects of *well-intentioned* actions are ethically permissible: Twycross[16] described how “treatment to relieve pain and suffering which coincidentally might bring forward the moment of death by a few hours or days is acceptable...but administering a drug such as potassium or curare, with the primary intention of causing death, is not”.

Twycross here contributed to a long-standing debate: what is the relevance of the double effect to clinical practice? Fohr[17] found “little evidence” that appropriately used pain medications would hasten death and concluded that “the risk of respiratory depression from opioid analgesic [was] more myth than fact”. The safety of analgesia and sedation when used carefully and titrated appropriately is clear, as illustrated by Davies et al[18]; the evidence suggests that it is only when prescribed inappropriately that side effects become a risk, as is the case for any other medication. Thus Davies et al concluded that the doctrine of double effect was “simply a concept that applies to any medical intervention in which clinicians use their judgement to weigh up the intended benefit versus possibly adverse side effects”. Thus its relevance lies in its use as a “reflective tool”, not in an attempt to justify inappropriate prescribing nor in prescribing treatment for challenging symptoms.

Thus, prescribing analgesics to treat pain is compassionate – a classic example of intervention aimed to alleviate suffering – and well-intentioned, but there is little evidence that analgesia hastens death. Thus the double effect is largely irrelevant here. Its invocation seems to relate to potential harm caused by overdose; from this perspective, one could surmise that the doctrine of double effect could be invoked for most medical treatments.

## COMPASSION AND SUFFERING IN PALLIATIVE MEDICINE

Clinical judgement and compassion are cornerstones of good medicine; this is the case too for palliative medicine, though it is unusual in both respects. Clinical judgement differs: the focus of clinical judgement shifts from a future elusive cure to the patient's present and their quality of life. Furthermore, uncertainty is somewhat reduced; as Shakespeare bluntly put it, "we were born to die" (*R&J*; III.4.4).

However, while death is inevitable, a good death is not: shortly before his premature death, Schwartz[19] discussed how "moments of exquisite compassion" "[made] the unbearable bearable". Notably, it was in his name that Schwartz rounds were developed, as a space in which professionals can discuss such situations and the personal difficulties (including compassion fatigue) they may provoke. Similarly, Riggs et al[20] recently found compassionate care to be the single greatest priority for end-of-life care amongst 78 bereaved next-of-kin.

Compassion then is clearly key, though how it takes effect is unclear. Perhaps one effect is its facilitation of the therapeutic relationship, enabling the development of an intimate understanding of the patient's distress such that total pain can be addressed. This is critical to comfort and represents a huge holistic challenge that faces every clinician: palliative medicine is not restricted in practice to the speciality.

What, then, is the role of compassion in the *absence* of suffering? This, after all, is the goal of palliative care: to minimise suffering and maximise quality of life. For Mannix[8], "most of the dying are getting on with living"; moreover, death itself is usually not a suffering at all but rather a slowing and changing of breath, a deepening of sleep. However, compassion is etymologically defined through suffering and Nussbaum[21] presupposes to compassion the presence of suffering that is significant, largely unmerited, and has the potential to be experienced by the observer. So, does the seeming absence of suffering that comes with successful palliation prohibit compassion? Or has compassion done its work in *enabling* a comfortable death, adopting the guardian role here in case pain rears its ugly head once more?

Mannix[8] analogises life with a rose, at its most beautiful just before shedding its petals. This is not new; Shakespeare describes in *Romeo and Juliet* "A lightning before death", when "men are...merry" (1597; *R&J* V.3.90). Death can reveal the most beautiful manifestations of the human condition: wordless love echoing through a vigilant wait; colossal courage in the contemplation of death on the one hand and continuing a forever-changed life on the other. To call on suffering – and thus perhaps compassion – as necessary to palliative care contradicts its depth: it is about much more than this.

## DELIVERING COMPASSIONATE CARE

In the 2013 Mid Staffordshire inquiry report, Robert Francis QC called for "an increased focus...on the practical requirements of *delivering* compassionate care" in the NHS. This raises multiple questions.

Firstly: can compassion be taught? This is controversial, though apprenticeship is an oft-cited possibility (see Larkin, 2016). Chadwick[22] pointed out that no one can dictate what staff members feel towards the patients they meet”; in response, Whitby[23] called upon the need for systems-level changes to *foster* compassion: “compassion cannot be mandated but it can be supported”. Chochinov[24] considers compassion a cornerstone to “dignity-conserving care” in his ABCD approach (Attitudes, Behaviour, Compassion and Dialogue) and discussed the “various channels” through which compassion can be “cultivated”; he included in this “exposure to the medical humanities” with the goal of achieving “insight into the human condition”. He noted that for some, “compassion slowly emerges with life experience”; thus perhaps being truly compassionate is less about one’s role as healthcare provider and more about one’s humanity.

Secondly: what *are* these requirements? Compassionate care necessitates recognition of the patient’s emotional needs, perhaps alongside the psychiatric principles of transference and counter-transference. Time and resources are critical; yet, health systems are under undeniable pressures. Trzeciak et al[25] set out how compassionate care might reduce costs for the healthcare system overall; however, once individual patients – the beneficiaries of resource allocation – become identifiable, compassion can skew prioritisation of care. Risk and probability are harder to handle when faced with a desperate patient and thus it is easy to see how investigations and treatments might be offered despite a low likelihood of their changing the outcome. The question, then, is who are we treating here: the patient and their needs, our own desire to have ‘helped’, or a combination of these?

Thirdly: what are the barriers? Perhaps the medical model itself is one such barrier: it is innately problem-solving, such that we see patients and immediately generate reams of lists of problems, differentials, management plans... Assumptions are inherent in this approach, which is efficient and effective until the problem at hand is not necessarily a problem at all: for example, a comfortable death. Challenging this problem-solving approach to care, Chochinov constructed the ABCD mnemonic for dignity-conserving care (Attitude, Behaviour, Compassion, Dialogue) discussed above in reference to Francis Weld Peabody’s writing that “the secret of the care of the patient is in caring *for* the patient”. Later Chochinov[26] elaborated upon this: “optimal therapeutic effectiveness” necessitates not just the doctor-to-patient “right care” but also the person-to-person “humanity” of “pay[ing] attention to *persons*”. The medical model runs the risk of reducing an individual to lists; we must be wary of this.

Finally: how do we know that we are achieving this? Within one UK hospice, Palfrey et al[27] found that different individuals conceived ‘compassionate care’ differently – how then do we meet expectations, and measure such context-specific achievements? Consider hydration: in most contexts, its withdrawal is an utter failure of care; however, in palliative care there is no evidence that intravenous fluids help. The recurrent theme in the literature is of the need for individualistic patient-centred care based on authentic concern.

## CONCLUSION

Compassion ultimately transcends medicine: it motivates global development as much as it does caregiving. Palliative care demands compassion, in its patient- and context-specificity and its

dependence on gentle intervention: however, so too does the world, and without compassion elsewhere, perhaps medicine would not exist at all.

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